
Every Child Deserves a Healthy Start in Life!



Newborn screening has long been recognized as an essential, life-saving, and effective preventive public health service that has identified thousands of babies each year in the United States who are born with a genetic or metabolic disorder. In many cases, detecting these disorders spells the difference between life and death for these babies; in other instances, identifying newborns with a disorder means that they can be treated and thus not face life-long disability or cognitive impairment. Now, with the advent of new screening technology, babies can be tested—and treated—for many more disorders than was possible in the past.

Facing the Facts

- About 4 million newborns are screened each year in the United States. Although each state provides for newborn screening, some states screen for as few as 4 disorders, and others screen for as many as 60.
- Concerned parents and parent organizations are urging their states to enact laws requiring state public health laboratories to screen for the maximum number of disorders even if no treatment exists for many of them. State legislators, with input from parents and parent organizations and expert advice genetic advisory boards, decide which tests their states will perform.
- Today, the cost for a panel of newborn screening tests can be as high as \$140 for each child.
- However, the estimated costs of developmental disorders that can be prevented by newborn screening range from \$500,000 to \$1 million over a child's lifetime, both for the direct costs of care and loss of productivity.
- Cutting-edge technology is available now that can test newborns for more diseases than is possible using conventional tests.
- Newborn screening clearly is “more than a test” because it involves follow-up care, counseling, and other important services. Yet a *critical* piece of any comprehensive newborn screening program begins with the test itself and with its reliability. Laboratories and parents must be confident that test results are accurate and that disorders are not missed.
- CDC’s Newborn Screening Quality Assurance Program is the *only* comprehensive source in the world for ensuring the accuracy of newborn screening tests.



Setting the Direction

For more than 25 years, CDC's Newborn Screening Quality Assurance program has provided training, consultation, proficiency testing, guidelines, and reference materials to participating laboratories throughout the United States and in other nations. This program also helps set the direction for future research into promising and sophisticated screening techniques that could identify disorders that currently cannot be determined in newborns.

At present, state public health laboratories receive no federal grants or other funds to purchase equipment or to assist with laboratory training or personnel costs, and CDC does not have the funds to help the states implement new testing methods or to develop new technologies for testing babies.

To meet the demand for sophisticated screening techniques, state public health laboratories need to be able to—

- Purchase the best instruments available to detect disorders. Precision instruments are available now that screen for more than 30 disorders in a single test.
- Hire and train laboratory scientists to perform the advanced testing.
- Make sure test results are accurate *every time for every baby*.

As well, CDC laboratory scientists must evaluate new screening technologies for existing tests and offer training in their use as well as explore new tests for diseases such as—

- Asthma (a chronic disease of the respiratory system).
- Diabetes (a disease that affects 17 million Americans and causes 200,000 deaths annually).
- Fragile X Syndrome (results in mental retardation, which, over successive generations, can be profound).
- Lysosomal storage diseases (about 46 disorders that lead to progressive physical and mental deterioration and early death).
- Severe Combined Immunodeficiency (SCID—a genetic disorder that affects a child's immune system).

A fundamental issue of newborn screening is whether we can identify and save more babies with life-threatening conditions by funding the development and use of the best laboratory technology available. Our goal is to give all babies the healthy start in life and a future that they deserve.

